Biobanks and Our Common Good

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Abstract There are many different kinds of biobanks with various scopes and purposes, such as diagnostic biobanks, therapeutic biobanks, and research biobanks. My focus is on research biobanks, which enable us to identify genetic and environmental causes of complex diseases. The hope is that research biobanks of this kind will be able to provide us with new medical knowledge of large public health issues. Research biobanks have the potential to produce knowledge that could hold great value and significance for many. In this mindset, such institutions may be considered a social asset benefiting all. I aim to explore the obligations we have in relation to research biobanks and what we can expect and demand from them. I argue that good reasons for everyone to participate in this type of research can be found in the principles and values that characterise modern societies and that many of us take for granted. To explore the rights and obligations, we have vis-à-vis biobank research. I base my arguments in a communitarian and liberalistic understanding of individuals and communities. These two approaches illustrate in separate ways what is at stake. We shall see that both approaches facilitate arguments claiming that biobank research is part of our understanding of ourselves and of society. This means that biobank research can become part of the kind of society that provides the individual with the opportunity to realise his understanding of a good life. If this is the case, we are not obligated to obtain consent from the individual in connection with biobank research. A central prerequisite is that the research promotes values and benefits we can all support. To safeguard this principle, a wider discussion and debate concerning what to research is needed. From this it follows that it could be unethical not to research certain diseases genetically.

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Introduction

Biobank research raises a number of questions concerning the relationship between the individual, society, and biobanks. What are the responsibilities of each stakeholder? What are their rights and obligations? What type of resource and asset does biobank research represent? How do we distribute this asset (Austin et al. 2003; Hansson and Levin 2003; Tutton and Corrigan 2004; Cambon-Thomsen 2004; Godard et al. 2004; Ashburn et al. 2000; Winickoff and Winickoff 2003; Sutrop 2004; Häyry et al. 2007; Gottweis and Petersen 2008)? Biobank research combines genetic data with health and lifestyle information (Holmen et al. 2003). If our "collective genetic legacy" can secure good health and prosperity for ourselves and future generations, the issue of whether it ought to be a duty to contribute to the realisation of this common good becomes highly relevant.

In medical research consent is a fundamental principle; nobody can be forced to participate in research if they do not give consent. More generally speaking, we do not accept setting aside individual rights for the greater good of the community. This mindset, in combination with an individualistic ethos, has led to a situation where people do not automatically volunteer for matters concerning the greater good of the community. Instead, it is argued that we have a moral duty to contribute to medical research (Rhodes 2005, 2008; Herrera 2003; Harris 2005; Harris and Woods 2001; Evans 2004; Orentlicher 2005). However, because medical research historically has been a subject for a number of scandals and abuse, this moral argument cannot be made too strongly; i.e., we cannot unduly judge the ones who do not participate nor can we make participation compulsory. It may appear that a moral standpoint is the only basis from which to argue that the individual ought to participate in biobank research. In this chapter it will be argued that good reasons for everyone to participate in this type of research can be found in the principles and values that characterise modern societies and that many of us take for granted. The condition is that biobank research does not constitute a breach with these principles and values. Freedom is such a principle, autonomy or self-realisation is another, and equality is a third. To explore the rights and obligations we have vis-à-vis biobank research, I will take as a point of departure first a communitarian and subsequently a liberalistic understanding of individuals and communities. In separate ways, these two approaches illustrate what is at stake. We shall see that both approaches facilitate arguments claiming that biobank research is part of our understanding of ourselves and of society. This means that biobank research can become part of the kind of society that provides the individual with the opportunity to realise his understanding of a good life.

Communitarianism, Society and Biobanks

Biobank research has brought to the fore the issue of whether the individual has certain obligations vis-à-vis the community. To a certain degree we can claim that all medical research benefits the individual, but the nature of biobank research has made this issue all the more pressing. Because biobank research is believed to constitute a social asset, communitarian values have become central, and several voices argue that we have obligations vis-à-vis the community as a whole, and that these obligations must be balanced with the rights of the individual (e.g. Chadwick and Berg 2001). Communitarian values, however, are based on a certain view of individuals and communities that often goes unexplained. The degree to which we commit to the communitarian values, thus, is dependent on whether or not we share this view. Consequently, it is meaningless to appeal to communitarian values without accounting for the views on which these values are based.

The communitarian view claims that "[o]nce we recognize the dependence of human beings on society, then our obligations to sustain the common good of society are as weighty as our rights to individual liberty" (Kymlicka 2002: 212; see also Sandel 1998; Taylor 1985b). If we are to make an argument for why we ought to contribute to biobank research, we must demonstrate that individual rights cannot be interpreted independently of our obligations to biobank research and our connection to the community in general. It is commonly held that the individual has certain rights. This evokes a sense of a "primacy of rights" and entails that our obligations to society are derived from, or are secondary to, these rights in some sense. Freedom is such a right, which makes it difficult to claim that biobank research is, or constitutes, a social asset which one is obligated to support. However, if it turns out that biobank research conveys central values in our society, values that help define our identity and sense of belonging, maybe the "primacy of rights" should be amended with a set of "politics of the common good".

Whereas liberalism is based on the belief that we are free to choose our goals and the type of life we want to lead, the communitarian understanding claims that the exercise of this freedom only makes sense on the basis that we discriminate between different values and which goals we seek to realise. Our understanding of freedom is based on the belief that some forms of freedom are more significant than others. What enables this understanding is the fact that we view objectives and purposes in light of what is important to us. We thus distinguish between significant and trivial forms of freedom depending on who we are and our understanding of ourselves. That having been said, we cannot determine what is significant by how strongly or how often we desire something. Instead, it seems as though some feelings and objectives are more important than others regardless of their strength or how often they occur. This is explained by the fact that we do not only have first-order desires, but also second-order desires, which are desires about desires. Taylor has dubbed this "strong evaluation": "We experience our desires and purposes as qualitatively discriminated, as higher or lower, noble or base, integrated or fragmented, significant or trivial, good and bad" (Taylor 1985c: 220; see also Taylor 1985a, 1998). In other words, we find that some of our feelings and objectives are intrinsically more significant or valuable than others. We discriminate between different values and feelings. This implies that our freedom is contingent on values and objectives about which we can be wrong.[1] If we act on the basis of these values we will fortify our "unfreedom" rather than our freedom. Freedom (or autonomy or self-fulfilment) cannot be understood independently of the values and objectives that give our actions meaning.

The right of the individual to choose not to participate in biobank research, to not contribute to this social asset, must be seen in light of which values and objectives give our actions meaning. Freedom of choice has no value in itself; the value is in the actions we do choose. The communitarian approach entails that the right of the individual to decide for himself cannot be separated from the objectives held by society. The self comprises objectives that we do not ourselves choose but discover as a result of being embedded in various social practices and contexts. Exercise of freedom thus does not mean that one is free to reject or revise one's objectives and projects, but that one is capable of fulfilling these by realising what the constituent parts of the objectives are. If the community, in part, constitutes our objectives, the common good will be part of the individual good. Our identity and connection with the community means that we are unable to view ourselves as separate from it. If biobank research constitutes a common good or a value from which we cannot separate ourselves, any fulfilment of this common good will mean that we fulfil our own understanding of the good life, because this understanding, in part, is founded on the common good. The best way to promote and serve the interests of the individual would be to limit the options of not participating, hence contributing to a realisation of the good life. The right to self-determination may undermine a central asset in society, and a fortiori undermine the opportunities the individual has to pursue his own projects, because these, in part, are based on society in general.

The communitarian understanding of how best to serve the interests of the individual entails a specific view of which type of society is the best. Consequently, this excludes other views, including the liberal one. We cannot appeal to communitarian values without simultaneously reflecting on the type of society in which we prefer to live. Whether communitarian values ought to constitute an argument in medical research in general, and biobank research in particular, is thus dependent on whether we commit to the communitarian understanding of individuals and communities on which these values are based.

If we look at the liberal understanding, the conception of the common good is based on the different preferences held by the individual. This approach states that the common good is to give the individual an opportunity to realise his understanding of the good life on an equal footing with the opportunities of others to pursue the same goal. Consequently, we can argue that the common good in a liberal society "is adjusted to fit the pattern of preferences and conceptions of the good held by the individuals" (Kymlicka 2002: 220). The communitarian view, however, interprets the common good taking a substantial understanding of the good life as defined by

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[1] The alternative is to claim that we can never be wrong in terms of our desires, which is only possible if our feelings are "brute facts". This position, however, is not very plausible. We distinguish between feelings such as pain on the one hand and shame and fear on the other. The former is a case of brute fact; if you do not feel pain, you are not in pain. The latter two, however, might be subject to mistakes; they may be irrational and thus unfounded, cf. Taylor 1985c: 222–227.

the community's way of life as its point of departure. The common good represents the standard by which the individual understanding of the good life is judged. If biobank research represents a common good in society, the individual's understanding of the good life will be evaluated on this basis. And because society's understanding of the common good involves ranking values and goals, the preferences that are in accordance with this common good will be emphasised more than others. The communitarian understanding is perfectionistic "since it involves a public ranking of the value of different ways of life" (Kymlicka 2002: 220). The consequences of this perfectionism could be that the individual is encouraged to participate in biobank research, while efforts are made to restrict his or her opportunities to refrain from contribution.

In the communitarian understanding lies the assumption that the good life may only be realised in a society maintaining the social conditions making it possible to form an opinion as to the kind of life one wants to lead. Biobank research is a common good serving as a foundation for the objectives the individual seeks to realise. By limiting the opportunities the individual has of not participating in biobank research, the social conditions facilitating self-determination are maintained. The communitarian view is that a substantial understanding of the common good is necessary to protect the freedom and rights of the individual. On the other hand, if an individual exercises his or her right not to participate in biobank research, he or she will undermine the conditions for realising his or her understanding of the good life, and you will thus be less free (Taylor 1985c).

Liberalism, Equality and Biobanks

Liberalism advocates a belief in the rights of the individual and the individual's right to make autonomous choices. This would appear to mean that liberalism may not be used as an argument in favour of contributing to biobank research: If liberalism involves the right to freely choose one's values, how can anyone claim that some choices are more right than others? If the value lies in the very freedom to choose and not in what is chosen, it is hard to see how contributing to common assets such as biobank research follows from a liberalistic point of view. However, we shall see that liberalism does not necessarily represent an argument against introducing a form of obligation to participate in biobank research, but rather constitutes an argument in favour of our participating. I argue that if we want to defend the basic values on which liberalism is based, we should also, with good reason, contribute to the kind of common good biobank research represents. The condition is that the biobank research can be said to constitute key values to which the individuals of a liberal society have committed. Which kinds of values are these?

Political theories appeal to various values, such as "contractual agreement", "the common good", "utility", "rights", and "identity". Does this mean that the various theories appeal to ultimately conflicting values? And does this mean that we have to choose one to the detriment of the others? In this case, the choice of theory will determine to which values we appeal. But how do we know which theory to choose in the first place? Which criterion do we use to determine which theory is the right one? There is no simple answer to this question, but Ronald Dworkin presented one possible solution that may show us a way out of the problem. He claims that modern political theories do not have different foundational values but that they rather share the same ultimate value, equality (Dworkin 1977: 179–183, 1983, 1986: 296–301, 2000; Sen 1992, 2004: 22; Cohen 1993). They are all "egalitarian" theories. Dworkin does not, in this context, refer to equal distribution of income or equal distribution of property. They are obviously not egalitarian in this regard. We can, however, interpret the term egalitarian as treating everybody "as equals". This is indicative of a more abstract and fundamental understanding of the concept, entailing that "the interests of each member of the community matter, and matter equally" (Kymlicka 2002: 4). Everyone is entitled to equal concern and respect. The question thus becomes which conditions must be met before this is the case. In this approach, one can argue that each political theory presents a distinct definition of what it means to treat people as equals. We must therefore look at the conditions that, according to liberalism, must be present in order for us to treat each other as equals.

Liberalism is grounded on a belief in the individual's right to freedom. In this lies the right to make autonomous decisions as well as the right to realise the understanding of how one wants to live. The only limitation on this right is another's right to the same freedom. Consequently, an individual has the right to as much freedom as is compatible with the others' rights to the same amount of freedom. Why does freedom have value? One possible answer to this question is the fact that it enables us to obtain the benefits we want. Freedom protects our interests. But as not all forms of freedom are equally important to us, it is common to distinguish between "basic liberties" and "non-basic liberties". Basic liberties include inter alia the "freedom of thought and liberty of conscience; the political liberties and freedom of association, as well as the freedom specified by the liberty and integrity of the person" (Mill 1859/2004: 15–16; Rawls 1999: 53, 2005: 291). By categorising these as basic liberties, Rawls does not only refer to how they are more important to us than other rights; they are necessary for us to be able to exercise our moral ability, and they are inalienable. In this context, however, the first sense is the most relevant: "the basic liberties" are necessary to obtain various understandings of the good life. This means that we must organise our society in such a way that we all have the same opportunities to realise our understanding of the good life, whatever our interpretation of it may be. Society does not determine what the common good is, but the common good is that society provides everyone with the opportunity to realise their understanding of how they want to live. If we distinguish between the means or goods which we need and the types of goals we ought to seek realised with the help of those goods or means, the former is the responsibility of society, whereas the latter is up to the individual. If goods exist that can be said to be necessary in order to realise one's understanding of the good life, goods that "have a use whatever a person's rational plan of life" (Rawls 1999: 54), the idea is that it is fair to give everyone equal access to these goods so that everyone has equal opportunity to realise the life they want to lead.

How do we justify social differences, such as some people making more money than others? One possible answer, and perhaps the most prevalent, is that these differences can be justified, given the existence of equality of opportunity. Under the premise of fair competition for offices and positions resulting in benefits, such as higher income and increased prestige and status, differences tied to these offices and positions may be justified. As long as no one is discriminated against on the basis of gender, race, or social background, economic differences in income are not unfair. What, then, of those worse off? According to this principle they cannot object to these differences, nor are they entitled to any of the benefits. Not everyone agrees with this principle, and as we shall see, there is good reason to expand the principle of equality of opportunity to include those worse off in such a way that they may also benefit from the differences.

What is it that makes equality of opportunity intuitively appear fair and just? This is primarily due to it being based on what people do and not who they are. What we end up as depends on our choices and not on our circumstances. It is not determined by our gender, race, or social background – conditions we are unable to do anything about.[2] Hence, we believe that social differences are justifiable if they are a consequence of the individual's choices and actions. Similarly, we find it unreasonable if differences are caused by social circumstances, such as gender or race. It becomes a question of what you deserve. What, then, of differences in natural abilities and skills? Similar to differences in social circumstances, these are not affected by individual choices, and as such are not up to the individual to determine. No one deserves being born into a particular social class, race, or gender. But the same premise seems to apply to natural differences; no one deserves being born with a disability or an extraordinary talent. Rawls thus concludes that "once we are troubled with the influence of either social contingencies or natural chance on the determination of distributive shares, we are bound, on reflection to be bothered by the influence of the other" (Rawls 1999: 64). The original intuition behind equality of opportunity was that economic differences ought to be determined by personal choices and actions and not by social advantages and disadvantages. If this is true, we must also make allowances for natural differences, as these are as little a result of personal choices and actions as are social circumstances. However, instead of levelling these differences the way we did with social circumstances, Rawls proposes that we permit these differences on the condition that they do not only benefit a few, but also those worse off (Rawls 1999: 54, 87). If some differences benefit all, nobody loses. In other words, we do not have to eliminate all differences, only those that work to someone's disfavour. Rawls calls this approach "the difference principle".

The principle of equality of opportunity and the difference principle are concerned with how we inter alia ought to distribute economic resources and how we can explain differences, such as, for example, differences in income. Rawls does not, however, concern himself much with the issue of health (Rawls 1999: 83–84, 2005: 21),[3] and it has thus been necessary to explain these principles to define

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[2] What it takes to actually achieve equality of opportunity is controversial, but it does not affect the argument in this context.

[3] On health as a "primary good", see Rawls 1999: 54. See also Rawls 2001: 173–174, 2005: 184–185 and 244–245.

the rights and obligations of individual's vis-à-vis the health benefits related to biobank research.[4] In the context of biobanks, health is interpreted as a result of environmental (social) circumstances and genetic (natural) conditions. One of the key characteristics of biobanks is the connection between genetics and health and lifestyle information, which enables us to explore complex causal connections in the interaction between genetics and environmental conditions. The fact that health is tied to natural differences follows from the roles our genes play. Some have a genetic makeup making them more prone to contract or develop a number of diseases, but it does not necessarily follow that this will happen. Environmental or social circumstances play a role in the risk people have of developing cardiovascular diseases, diabetes and cancer.[5] A person does not pick one's genes or one's social circumstances.[6] If health is a good not only affecting one's well-being, but also the chances of securing other social goods, it follows from the principle of equality of opportunity that social differences related to health must be levelled, whereas natural differences ought to benefit those worst off. Only then do we treat people as equals. In other words, it is unfair that some people benefit from advantages that are not a consequence of their own choices and actions.[7]

What, then, are the consequences for the individual in terms of participation in, and contribution to, biobank research? First, the benefits and values produced by biobank research will contribute to levelling social differences related to health, because many of the diseases which biobanks study are related to socioeconomic conditions. One can compensate for these social differences by other means, but as long as a number of the most common diseases seem to be associated with social factors, new knowledge and insights gained from biobank research will remain one of the most important tools to fighting social differences caused by health issues. In other words, health benefits and assets must be distributed in such a way that we level differences and give everyone equal access. This entails that the individual ought to participate in, and contribute to, biobank research, because this

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[4] But Norman Daniels has quite successfully tried to apply Rawls' principles to the issue of health, focusing on health care and health need and allocation of scarce resources; see Daniels 1981, 1985, 2004, 2008, and Pogge 1989: 181–196. Less emphasis has, however, been placed on the application of these principles to problems related to biobank research within bioethics.

[5] A number of studies, surveys and reports have shown that social differences with regard to health are derived from variables such as class, race, gender and geographical belonging; see Black and Morris 1992; Marmot et al. 1978; Marmot 2004: 49–50; Marchand et al. 1998; Mackenbach et al. 2008; Daniels et al. 1999; Daniels 2008, Chap. 3.

[6] Rawls refers to health as a "natural primary good" and not a "social primary good"; see Rawls 1999: 54. In the context of biobank research it is, however, also appropriate to interpret health as a "social primary good"; see Daniels 1981, 2008.

[7] A possible objection could be the argument that health is a personal and not a social responsibility. It will thus not seem fair that differences in health are to be levelled if they are a consequence of personal choices and actions. This objection is not decisive for my argument as biobank research looks at the interaction between genetics and environmental conditions in relation to the risk of developing or contracting diseases based on this complex causal condition. It is also not given that personal choices and actions are enough to explain differences when it comes to health, and the personal responsibility for health argument should thus only play a minor role (Wikler 2004); but see Shapiro 2007.

is a prerequisite for producing the knowledge and insight needed to compensate for diseases caused by social circumstances. Second, biobank research will benefit those most at risk for developing diseases for which one is genetically disposed. As nobody picks their own genes, this means that differences in terms of the risk (disposition) of developing a disease are random. They are expressions of brute luck and not based on what a person may or may not deserve. We can imagine that individuals not particularly at risk for diseases stand to receive a larger share of the social assets, whereas those with a genetic disposition for developing a disease stand to receive a smaller share of the assets. This means that persons with a genetic disposition for developing the diseases biobanks want to research have the most to gain from this type of research, whereas persons who do not have this genetic disposition have little to gain. Differences in the genetic disposition for developing certain diseases should neither be an advantage nor a disadvantage for the individual in terms of access to assets, as these differences are not an expression of choice. However, instead of thinking that nobody should benefit from these differences, we should let the differences benefit all so that those worse off will also benefit. People not genetically disposed to develop certain diseases cannot use this as an argument to evade contribution, because that would mean that they used their advantage in a way that would increase, not reduce differences. This conflicts with the idea of treating everybody as equals, because it would only promote the interests of some groups, not all. However, if one contributes to biobank research, the position of those worst off will also improve in spite of differences in their genetic disposition for developing diseases, assuming that the risks are equally distributed among these groups (or that the worst off gain the most).

Biobank Research and Informed Consent

Biobank research does not accomodate arguments for obtaining consent as easily as other types of medical research. The question then is to what extent it is reasonable to require consent in biobank research. Moreover, if consent is indeed required, what type of consent would be relevant in this context (Hoedemaekers et al. 2007; Hansson et al. 2006; Hansson 1998; Beskow et al. 2001; Kaye 2004; Wendler 2002; Chadwick 2001). In my view, there is good reason to argue that consent is unnecessary if biobank research promotes and preserves values and assets with which we all agree in principle. This does not mean that all types of biobank research fall into this category. We must thus distinguish between the types of biobank research where obtaining consent is necessary and justified and the types of biobank research where this need does not exist. In order for biobank research to be exempt from the requirement of obtaining consent, the research must be entirely uncontroversial. We can assume that this category concerns research into diseases affecting a broad majority of the population. The research must apply to the population at large and not just affect a few select groups. Diseases falling into this category affect a large share of the population, and we must all relate to them in one way or another.

The nature of the values and benefits produced by biobank research in this regard must also potentially be made available to everyone, and the benefits must contribute to levelling social and natural differences.

This approach calls for a descriptive (neutral) rather than normative (perfectionistic) understanding of biobank research. We are talking about an asset necessary for realising the good life, irrespective of what our understanding of what that is.[8] Biobank research may be interpreted as a necessary means to ensuring that the individual attains his goals. Therein lies the claim that biobank research is a common good: it is an asset needed by everyone to realise their understanding of the good life. The usage of the term common here thus refers to it being a means everyone needs, and not that it ought to be used for a joint purpose to which everyone agrees. The problem of referring to biobank research as a common good in the normative sense is that this approach is based on a substantial understanding of the individual, as well as a perfectionistic understanding of society. If, implicit in the appeal to participate, there is an understanding of which is the worthier choice (to contribute to research) and which are the right ideals (communitarian). One could potentially alienate the individuals who do not share this view. Relying on a normative argument will fall short in a pluralistic society if the argument encapsulates values with which only part of the population can identify. Rather than constituting a collective (common) good, it may be perceived as divisive.

Instead of basing biobank research on the requirement of obtaining informed consent, there may be other and better ways of safeguarding the best interest of the individual. One option is to replace the requirement of consent with the opportunity to influence the topic of the research. This would enable the individual to exercise autonomy on a very different level than what is possible through the requirement of consent. In this way, the problems related to normative arguments in favour of biobank research are eliminated by having the individual participate in deciding the topic of research. Part of the problem of normative arguments in favour of biobank research is taking the values appealed to for granted. We can, however, not presume that a consensus as to which values to appeal to exists independently of the values held by individuals. If, on the other hand, we allow individuals to participate in deciding the topic of research, we solve this problem. Hence, we could say that biobank research is made accountable and ethical questions are seen in the light of the topics chosen for research.

One argument in support of requiring informed consent in biobank research is the right to privacy. If the right to privacy is critical, obtaining consent will be a way to safeguard this right. I would, however, like to address the issue of whether this right should be critical. The right to privacy is intuitive. Nobody likes it when it is violated or threatened. But even if a person dislikes actions which infringe on his right to privacy, it does not necessarily follow that these acts are impermissible. Freedom of speech comes to mind. Exercising one's right to free utterance may

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[8] See Rawls' concept of "primary goods": "Primary goods … are things which it is supposed a rational man wants whatever else he wants" (Rawls 1999: 79). See also Rawls 1999: 54–55 and 79–81, 2005, lecture V. Rawls also refers to primary goods as "all-purpose means" (Rawls 2001: 57–61).

cause another individual to feel that his right to privacy has been violated. Yet, very few are convicted of defamation. The reason for this, of course, is that we regard the right to free speech as so fundamental that we are willing to go to great lengths to protect it. Consequently, there will be times when we will have to put up with situations we dislike or find uncomfortable. If biobank research is based on information that cannot be traced back to the individual, and offers information at group level, so that the information presented does not apply to the individual, we have to ask ourselves whether the right to privacy ought to be so strong that obtaining consent is necessary. If other, weightier concerns exist, the right to privacy and consent may have to yield, even if the persons involved do not agree. This does not, however, necessarily mean a breach with the fundamental rights granted to the individual. Whether or not this is the case will depend on whether the right to privacy in this context may be fairly interpreted as being part of the fundamental rights granted to all. If the right to privacy constitutes such a fundamental right, the issue becomes whether this right should take precedence in the event it conflicts with other rights. In other words, the right to privacy may conflict with other rights granted to us, and the right to privacy cannot be interpreted as always being opposed to, or conflicting with, social or community interests.

Conclusions

The right of the individual to determine whether or not he wants to contribute to a common good, such as biobank research, comes off as problematic in light of the limited risk this poses to the individual. When the degree of risk for the individual is so low, and the potential gain for society is so great, it is justified/legitimate to ask whether the right to self-determination and the requirement of informed consent should carry as much weight in biobank research compared to other forms of medical research where the risk to the individual is considerably greater (WHO 2003; Helgesson and Eriksson 2008). Genetic research in general and biobank research in particular "has been accompanied by a shift in emphasis towards the ethical principles of reciprocity, mutuality, solidarity, citizenry and universality." (Knoppers and Chadwick 2005: 75). Even though biobank research forces issues related to communitarian values and principles, one should perhaps still question the communitarian understanding of individuals and society. In this context, one should especially emphasise the fact that a communitarian approach may imply a form of paternalism (Berlin 2002; Taylor 1985c: 229), which would make basing the argument for biobank research on communitarian values difficult.

In western democratic societies the position of the liberal egalitarian tradition is strong. It is thus wise to be sceptical of the increased emphasis on communitarian values and principles in the biobank debate. If communitarianism promotes an understanding that the self does not precede but comprises its objectives (given the social context) as well as a perfectionistic (non-neutral) understanding of the common good (as defined by the community's way of life), we must ask ourselves if we are willing to give up the liberal egalitarian understanding. This is founded on the belief that everyone should have equal opportunities to realise their objectives (whatever an individual's understanding of the good life may be), and it presents an antiperfectionistic understanding of society, in the sense that the common good is defined based on the kinds of means and resources needed and not the types of objectives that ought to be sought using these means and resources. It may appear that the concepts of "solidarity", "community" and "benefit" have become the new "buzz-words" of biobank research, but it is important to clarify the theoretical foundation on which these concepts are based. Perhaps the argument that one is obligated to contribute to biobank research could bring about a discussion as to which topics to research (Williams 2005; Williams and Schroeder 2004). In my opinion the interests of the individual are better served not by the requirement of informed consent but by a discussion of what is our common good resulting from participation in biobank research (Weldon 2004). In that case, contributing to biobank research would be a natural extension of the liberal values and democratic principles on which our society in general and medical research in particular are founded.

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